

Citizens' Health Care Working Group

HEALTH CARE
THAT WORKS FOR ALL
AMERICANS

OVERVIEW

Participants at the Citizens' Health Care Working Group Providence community meeting expressed great displeasure with the current health care system. Many issues, from cost to coverage to personal knowledge of medical needs, were discussed in regard to accessiblity. Participants felt the system was too complex and failed to treat the individual as a whole person.

The best solution to these health care issues, according to a majority of the participants, is a comprehensive, national program that provides access and coverage to all Americans regardless of age or income. The program would be funded through a progressive tax system, thus requiring all to pay, but by ability according to income. There was also support for improving issues of access and quality for minority populations.

When asked about employer funded insurance, participants were hesitant to give any positive feedback. Only under the stipulation that a national universal system was unavailabe was it considered acceptable. Most attendees believed public policy should no longer use the tax rules to encourage an employer based system.

Many participants were displeased with the concept of tradeoffs and were unwilling to vote on questions that they considered unfair. They strongly believed that America could provide quality, universally accessible coverage in an equitable and efficent manner. There was a desire for distribution at a local level, to ensure cultural sensitivity and a strong public health system.



Citizens' Health Care Working Group Community Meetings

Kansas City, Missouri Orlando, Florida Baton Rouge, Louisiana Memphis, Tennessee Charlotte, North Carolina Jackson, Mississippi Seattle, Washington Denver, Colorado Los Angeles, California



Providence, Rhode Island

Miami. Florida Indianapolis, Indiana Detroit, Michigan Albuquerque, New Mexico Phoenix, Arizona Daytona Beach, Florida Upper Valley, New Hampshire Hartford, Connecticut Des Moines, Iowa Philadelphia, Pennsylvania Las Vegas, Nevada Eugene, Oregon Sacramento, California Billings, Montana San Antonio, Texas Fargo, North Dakota New York, New York Lexington, Kentucky Little Rock, Arkansas Cincinnati. Ohio Sioux Falls. South Dakota Salt Lake City, Utah

SESSION FINDINGS

Values

The most important attribute for "Health Care That Works For All Americans" identified by the group was, by a large margin, that it should be universal, everyone should have access. This was followed by the concept that comprehensive care, from prevention to treatment to long-term care, was a right. Equity and affordability were also key values. The vast majority of attendees (94 percent) believed that it should be public policy that all Americans have affordable health care coverage.

As we consider ways to improve our health care system, what values and/or principles do you believe are fundamental?

Top 5 responses listed below

- Access for everybody
- Comprehensive (prevention through treatment) - long-term care as a right.
- Equity
- Affordability (across lifespan)
- Culturally appropriate and sensitive

Benefits

Care should be provided for everyone. Groups are constantly changing and resources are wasted in determining eligibility.

Separating people into groups innately creates inequality, but we have to make sure the defined level of services is not spread too thin.

The majority of participants (83 percent) believed that providing a defined level of services for everyone was preferable to categorical coverage such as the current system. One table reported, "We believe it could be a single streamlined system with one funder." It was noted, though, that some populations need specialized care, more than a basic set of services.

Of the additional benefits that might be added to the prototype benefits package, the most popular choice was care provided by nurse practitioners and other non-physician providers. This was followed closely by coordination of care; interpretation services; and health education, particularly around prevention. When asked about reducing the benefits package, there was strong support for eliminating "indiscriminate access to high-cost tests," with some support for eliminating chiropractic care.

In deciding who should determine the content of a basic benefits package, participants put most confidence in consumers, then medical professionals, then government, first Federal and then state and local. Attendees believed that employers and insurance companies should have input into deciding the package but at a lower level.

Getting Health Care

Problems getting health care revolved around issues related to access. Some of these were related to insurance coverage, such as limited access to certain covered services, problems with portability and the insurance enrollment cycle. Access problems were exacerbated for the uninsured. Problems related to access included: language barriers, transportation and child care. Cost was raised as a prevailing issue. Common difficulties included: lack of knowledge of what is needed and/or available, "getting past the receptionist" and long waits for appointments. People noted the complexity of the system, citing Medicare Part D as an example. One person commented that it is difficult to do paperwork when you are sick. Another discussed that care too often is compartmentalized and that health care does not consider the person as a whole.

Among the attributes attendees found most important in getting care were: choice of provider, including access to advanced practice nurses; coordinated services; equity in quality and access to care; the physician-patient relationship; not having to worry about costs and a holistic approach.

Financing

Enrolling everyone in a single pool would spread costs and yield savings.

Three quarters of attendees who voted believed that everyone should be required to enroll in basic health care coverage, either private or public. Many participants chose not to vote on this item, because as one person said, "it is an unfair question." One person noted a fear that "basic" coverage might take the form of a health savings account, and that if not structured correctly could cause major problems for individuals with serious health problems. Another said that the government can require many things but was not sure whether participation in health coverage was one of them. Close to half believed that those with higher income should pay more, although many participants chose not to vote on this item. With regard to

What should the responsibilities of individuals and families be in paying for health care?

Top 5 answers are listed below

- Commitment within family to focus on wellness.
- Being an active participant/partner in care (advocate for self).
- If you work, you should pay some amount towards system
- Progressive tax system (everyone participates).
- Cost-sharing (individual should bear some risk).

penalizing unhealthy habits, one person remarked, I don't think we should penalize people for their lifestyles, but we should be responsible for educating people to get them on the right track." Another person noted that low-income people are more likely to smoke and penalizing them risks serious inequity.

The majority of attendees (74 percent) believed that current tax rules encouraging employers to provide health insurance should not be continued, but there was strong dislike for this question and some participants chose not to vote. Attendees felt "boxed in" by the question. This was based on a view that a major change was needed, disconnecting coverage from employment. There was support for funding the transformed system through taxes. In the absence of a national plan, there was

support for employers to be responsible, with breaks for small businesses. One person noted that he didn't like employer subsidies because they were invisible to the citizen, unlike Medicare or Medicaid whose costs are frequently cited.

The most important responsibilities for individuals and families in health care were committing at the family level to wellness, being an active participant/partner in one's care and making a financial contribution to the system, if you work. There was also support for a progressive tax system in which everybody participates.

Attendees offered a long list of steps that could be taken to slow the growth of health care costs including: getting "profit" out of health care, eliminating direct to consumer pharmaceutical advertising, considering lower cost alternatives for where care is delivered and who provides it, encouraging hospice care at the end of life, focusing on evidence-based medicine and prevention and decreasing costs associated with malpractice.

Although some attendees objected to the question, roughly four fifths were willing to pay more to support efforts leading to affordable health care coverage for all Americans. Roughly one quarter of participants were willing to pay as much as \$1,000 a year or more.

The three highest priorities for public spending ranked by this audience, were guaranteeing that all Americans have health insurance, support for public health programs and funding programs that help eliminate problems in access or quality of care for minorities.

Tradeoffs and Options

Many participants resisted the notion of trade-offs. Some attendees were willing to give up some choice, or high cost interventions in exchange for broader access. One medical student, not entirely facetiously, said he'd accept a job at a low salary in exchange for his quarter million dollar educational debt. One person argued for building off the current Medicare system, saying, "It's universal, you turn 65, you get a card and you're good to go. Why not learn from this?"

The proposal participants ranked highest for ensuring access to affordable high quality coverage was creating a national health insurance program, financed by tax payers through which all Americans would get their insurance. There was also strong support for expanding neighborhood clinics, requiring all Americans to enroll in basic health care coverage and opening up enrollment in national federal programs like Medicare or the Federal Employees Health Benefits Program.

If you believe it is important to ensure access to affordable, high quality health care coverage and services for all Americans, which of these proposals would you suggest for doing this?

(listed in order from highest support to lowest)

- Create a national health insurance program, financed by taxpayers, in which all Americans would get their insurance.
- Expand neighborhood health clinics.
- Require that all Americans enroll in basic health care coverage, either private or public.
- Open up enrollment in national federal programs like Medicare or the federal employees' health benefit program.
- Increase flexibility afforded states in how they use federal funds for state programs (such as Medicaid and S-CHIP) to maximize coverage.

At the close of the meeting, when asked for what had been missing from the discussion, interesting perspectives emerged. One person noted the need to shift from the current procedure based approach to payment. "When we pay for doing things, we'll get more of them." Another noted that the focus had been on the individual and the family, not the community. A person stated that prevention doesn't get adequate attention, because the benefits associated with preventive services do not accrue immediately to those making payments. The issue of care for the undocumented also came up.

Richard Frank closed the meeting by thanking the group and saying he had heard what they didn't like and what they did and that the meeting had contained the right mix of passion, conviction and willingness to struggle with issues. He suggested participants go the Working Group website and "blog the people to death" to make their views known to a broader audience.

METHODOLOGY

Participants at the meeting sat at tables of eight to ten people, each with a volunteer facilitator. The meeting format was a mix of table-level discussion, reporting table findings to the full group, quick surveys using electronic keypads and full group discussion sessions. Main points from the table discussions were called-out to the full group and displayed on a screen. Participants answered questions and ranked choices using keypads after which the results were displayed. Findings from these polls formed the basis for full group discussion. Complete polling data from this meeting is available in the Data section of this report and online at www.citizenshealthcare.gov

PARTICIPATION

This meeting was co-hosted by the Rhode Island Public Health Association, whose President, Dr. Sharon Marable, welcomed the group. Ron Winter, President Elect of the Association, provided help in organizing the meeting. Others who assisted in planning the meeting included Senator Jack Reed's office, the Black Ministers' Alliance and the Rhode Island Area Health Education Center. A supper was provided by the Neighborhood Health Plan. Richard Frank represented the Working Group and there were roughly 60 people in attendance. He urged attendees to speak from the heart to try to identify what solutions "are most bearable."

Meeting attendees were predominately female (63 percent). The age distribution differed from other Working Group meetings, with somewhat younger people in attendance: about 11 percent of attendees were under 25; 39 percent were between 25 and 44; 36 percent were aged 45 to 64 and 14 percent were over 65. Seventy-seven percent of attendees were white. Seven percent identified themselves as Hispanic/Latino. As has been the case at other meetings, attendees were well educated, with 34 percent with a bachelor's degree and 46 percent with even higher levels of education. Seventy-two percent of the audience had employer-sponsored

health insurance and an additional nine percent had self-purchased insurance. Nine percent were Medicare beneficiaries, but there were no Medicaid recipients in attendance.

Charles Schwartz, Executive Director of the Institute for Labor Studies & Research of Cranston, Rhode Island, interviewed several participants for a documentary film on health care which his organization is making.

DATA

Are you male or female?

37.20% 1 Male 62.80% 2 Female

How old are you?

11.40% 1 Under 25 38.60% 2 25 to 44 36.40% 3 45 to 64 13.60% 4 Over 65

Are you Hispanic or Latino?

6.80% 1 Yes 90.90% 2 No

2.30% 3 No Response

Which of these groups best represents your race?

76.70%
1 White
14.00%
2 Black or African American
2.30%
3 Asian
0.00%
4 Native Hawaiian or Pacific Islander
0.00%
5 American Indian or Alaska Native
0.00%
6 Other

7.00% 7 Decline to answer

What is the highest grade or year of school you completed?

0.00% 1 Elementary (grades 1 to 8) 0.00% 2 Some high school 6.80% 3 High school graduate or GED 6.80% 4 Some college 4.50% 5 Associate Degree 34.10% 6 Bachelor's Degree 7 Graduate or professional degree 45.50% 2.30% 8 Decline to answer

What is your primary source of health care coverage?

71.70% Employer-based insurance 8.70% 2 Self-purchased insurance 2.20% 3 Veterans' 8.70% 4 Medicare 0.00% 5 Medicaid 4.30% 6 Other 2.20% 7 None 2.20% 8 Not sure

What is your employment status?

14.60%46.30%Self-employedEmployed - working full time

12.20% 3 Employed - working part-time

4.90%	4	Not employed / currently looking for work
2.40%	5	Homemaker
19.50%	6	Other

Which one of these statements do you think best describes the U.S. health care system today?

56.50%	1	It is in a state of crisis
37.00%	2	It has major problems
6.50%	3	It has minor problems
0.00%	4	It does not have any problems
0.00%	5	No opinion

Which one of the following do you think is the MOST important reason to have health insurance?

57.80%	1	To pay for everyday medical expenses
40.00%	2	To protect against high medical costs
2.20%	3	No opinion

As we consider ways to improve our health care system, what values and/or principles do you believe are fundamental? And which of the following values/principles is most important to you?

,		
36.40%	1	Access for everybody
9.10%	2	Affordability (across lifespan)
20.50%	3	Comprehensive (prevention through treatment long-term) care as a right
2.30%	4	Access according to needs
4.50%	5	Caring community mindset
13.60%	6	Equity
4.50%	7	Consumer-friendly
6.80%	8	Culturally appropriate and sensitive
2.30%	9	Providers have resources to provide care

Should it be public policy that all Americans have affordable health care coverage? [By public policy we mean that the stated public goal is set out in federal or state law.]

93.50%	1	Yes
6.50%	2	No

Which of the following statements most accurately represents your views?

Providing coverage for particular groups of people (e.g. employees, elderly, low-

17.40% 1 income, etc.) as is the case now

Providing a defined level of services for everyone (either by expanding the

82.60% 2 current system or creating a new system)

It would be difficult to define a level of services for everyone. A health plan that many people view as "typical" now covers these types of benefits, many of which are subject to copayments and deductibles:

Preventive Care—screenings, routine physicals, influenza and pneumonia immunizations, well child care, limited dental care

Physicians' Care—inpatient services, outpatient surgery, related tests, home and

office visits, medical emergency care Chiropractic Care

Maternity Care
Prescription Drugs

Hospital/Facility Care—inpatient and outpatient services

Physical, Occupational, and Speech Therapy

Mental Health and Substance Abuse—inpatient and outpatient facility and professional care

How would a basic package compare to this "typical" plan?

Of the most frequent answers the group gave, what would you add?

9.80%	1	Expanded dental care
2.00%	2	Expanded mental health care / substance abuse
15.70%	3	Increase nurse practitioners and other providers
2.00%	4	Assisted living / hospice care
11.80%	5	Expanded benefits for children (under 18)
13.70%	6	Education (preventive care)
5.90%	7	Complimentary /alternative care
13.70%	8	Interpretive/language services
11.80%	9	Long-term care
13.70%	10	Coordination of care

Repoll: Of the most frequent answers the group gave, what would you add?

6.10%	1	Expanded dental care
8.20%	2	Expanded mental health care / substance abuse
16.30%	3	Increase nurse practitioners and other providers
6.10%	4	Assisted living / hospice care
10.20%	5	Expanded benefits for children (under 18)
12.20%	6	Education (preventive care)
4.10%	7	Complimentary /alternative care
12.20%	8	Interpretive/language services
8.20%	9	Long-term care
16.30%	10	Coordination of care

Of the most frequent answers the group gave, what would you take out?

37.00%	1	Indiscriminate access to high-cost tests
19.60%	2	Chiropractic care
4.30%	3	Designer prescription drugs
8.70%	4	Expensive medical technologies
30.40%	5	Nothing

On a scale of 1 (no input) to 10 (exclusive input), how much input should each of the following have in deciding what is in a basic benefit package?

3rd	4.128	Federal government
4th	3.804	State and/or local government
2nd	6.813	Medical professionals
6th	2.327	Insurance companies
5th	2.750	Employers
1st	8.021	Consumers

What kinds of difficulties have you had in getting access to health care services? And which of these kinds of difficulties is the most important to address?

- 1 Language barriers
- 2 Doctor did not listen/believe
- 3 Lack of appropriate child care to enable access
- 4 Transportation

- 5 Lack of access to specialty care
- 6 Cost
- 7 Lack of access to a preferred provider
- 8 Lack of knowledge and education about what is needed and available
- 9 Lack of insurance
- 10 Getting beyond receptionist

What kinds of difficulties have you had in getting access to health care services? And which of these kinds of difficulties is the most important to address?

- 1 Long wait for an appointment
- 2 Unequal treatment based on race
- 3 Difficulty getting time off work
- 4 Change of job/insurance prevent access
- 5 Health insurance limits access (no coverage for certain service)
- 6 Complexity
- 7 Time cycle of getting into insurance coverage
- 8 Hard to do paperwork when sick
- 9 Lack of coordination of care
- 10 Lack of providers

In getting health care, what is most important to you?

- 1 Choice of physician
- 2 Access to advanced-practice nursing and generalists
- 3 Coordinated services
- 4 Equal quality and access to care
- 5 Physician/patient relationship
- 6 Competency of care
- 7 Cost
- 8 Holistic approach
- 9 Education

Should everyone be required to enroll in basic health care coverage - either private or public?

76.00% 1 Yes 24.00% 2 No

Should some people be responsible for paying more than others?

79.20% 1 Yes 20.80% 2 No

What criteria should be used for making some people pay more?

20.40%
2.00%
2 Family size
26.50%
3 Health behaviors
44.90%
4 Income
6.10%
5 Other

Should public policy continue to use tax rules to encourage employer-based health insurance?

26.50% 1 Yes 73.50% 2 No

What should the responsibilities of individuals and families be in paying for health care?

2nd	Being an active participant/partner in care (advocate for self)
1st	Commitment within family to focus on wellness
3rd	If you work, you should pay some amount towards system
4th	Progressive tax system (everyone participates)
5th	Cost-sharing (individual should bear some risk)
6th	Consequences for unhealthy/risky behaviors

Which of these steps is the most important to take in order to slow the growth of health care costs in America?

- 1 Decrease cost of liability/malpractice
- 2 Get profit out of medicine (esp. insurance companies); less business influence
- 3 More investment in primary care infrastructure
- 4 Examine recent increases in maternity care (e.g. c-sections)
- 5 Eliminate/reduce pharmaceutical advertising
- 6 Focus on preventive care
- 7 Encourage hospice care to reduce end-of-life care costs
- 8 Examine where care is delivered (e.g. home vs. hospital)
- 9 Use existing successful models of care (evidence-based care)
- 10 Increase accessibility to medical devices and equipment

Which of these steps is the most important to take in order to slow the growth of health care costs in America?

- 1 Reduce stress using complementary care
- 2 Reduce unnecessary studies
- 3 Legalize drug importation
- 4 Education in public schools about health education
- 5 Equalization of cost for services
- 6 Reduce duplication of expensive hospital machinery
- 7 Follow the money
- 8 Remove measures that protect pharmaceutical company profits
- 9 Invest in collaboratives

How much more would you personally be willing to pay in a year (in premiums, taxes, or through other means) to support efforts that would result in every American having access to affordable, high quality health care coverage and services?

23.70%	1	\$0
7.90%	2	\$1 - \$100
21.10%	3	\$100 - \$299
15.80%	4	\$300 - \$999
23.70%	5	\$1,000 or more
7.90%	6	Don't know

On a scale from 1 (low) to 10 (high), please rate each of the following public spending priorities to reach the goal of health care that works for all Americans.

5th	Guaranteeing that there are enough health care providers, especially in areas such as inner cities & rural areas
	Investing in public health programs to prevent disease, promote healthy lifestyles,
3rd	and protect the public in the event of epidemics or disasters
1st	Guaranteeing that all Americans have health insurance
	Funding the development of computerized health information to improve the
7th	quality & efficiency of health care

	Funding programs that help eliminate problems in access to or quality of care for
2nd	minorities
	Funding biomedical & technological research that can lead to advancements in
8th	the treatment & prevention of disease
	Guaranteeing that all Americans get health care when they need it, through
4th	public safety net" programs (if they can not afford it)."
6th	Preserving Medicare & Medicaid

If you believe it is important to ensure access to affordable, high quality health care coverage and services for all Americans, which of these proposals would you suggest for doing this? Please rate each of the following proposals on a scale from 1 (low) to 10 (high).

Offer uninsured Americans income tax deductions, credits, or other financial		
9th	assistance to help them purchase of private health insurance on their own.	
	Expand state government programs for low-income people (eg. Medicaid & S-	
8th	CHIP) to provide coverage for more people without health insurance.	
	Rely on free-market competition among doctors, hospitals, other health care	
	providers and insurance companies rather than having government define	
10th	benefits and set prices.	
	Open up enrollment in national federal programs like Medicare or the federal	
4th	employees' health benefit program	
	Expand current tax incentives available to employers & their employees to	
7th	encourage employers to offer insurance to more workers & families	
6th	Require businesses to offer health insurance to their employees	
2nd	Expand neighborhood health clinics	
	Create a national health insurance program, financed by taxpayers, in which all	
1st	Americans would get their insurance	
	Require that all Americans enroll in basic health care coverage, either private or	
3rd	public	
	Increase flexibility afforded states in how they use federal funds for state	
5th	programs (such as Medicaid and S-CHIP) to maximize coverage	

STAYING INVOLVED

Through the Citizens' Health Care Working Group website, we have made it possible for you to stay involved in the discussion – and to encourage others to get involved as well. Visit the website at www.citizenshealthcare.gov and:

- Download a Community Meeting Kit to plan a meeting for your family, friends, neighbors and co-workers.
 www.citizenshealthcare.gov/community/mtg kit.php
- Find a list of other cities hosting meetings and spread the word to friends and family in those cities to **Register for a Community Meeting** near them. www.citizenshealthcare.gov/register
- Add your opinions to three different polls in the Public Comment Center www.citizenshealthcare.gov/speak_out/comment.php
- Read what members of the Working Group and other Americans have to say by following the link on the homepage to the Citizens' Blogs.
 www.citizenshealthcare.gov
- Share your opinions on the future of health care by creating your own blog by following the link on the homepage to the Citizens' Blogs.
 www.citizenshealthcare.gov
- Join a growing group of individuals engaging in back-and-forth discussions on the **Discussion Forums** by following the link on the homepage. www.citizenshealthcare.gov
- Read Community Meeting Reports from other cities to see how opinions are shaping up across the country.
 www.citizenshealthcare.gov/community/mtng_files/complete.php
- Stay tuned to the homepage for the Citizens' Health Care Working Group
 Preliminary Recommendations (available in early June) and get involved in the 90-day public comment period.

 www.citizenshealthcare.gov
- Stay tuned to the homepage for information on the Final Recommendations and the schedule of Congressional hearings to address those recommendations.
 www.citizenshealthcare.gov

If you have additional ideas on how to get others involved, we would love to hear them. Please contact Jessica Federer at 301-443-1521 or jessica.federer@ahrq.hhs.gov.